

NODE NEWS

MEMBER NEWSLETTER | DECEMBER 2018

LYMPHOMA
COALITION

Worldwide Network of
Lymphoma Patient Groups



Dear LC Members,

As December winds down and my role as CEO begins to conclude, I reflect on the family that Lymphoma Coalition is. It is not easy to step away as I retire. This family has seen each other personally through a lot, including the loss of fellow coalition members, hard fought advocacy wins for patients, many Global Summits of both intense learning and great fun (that hotel/city that should not be named especially), generous best practice sharing that is not seen in any other organisation and a place where we can all turn to when we need support and advice to support the patients we care so much about. Congratulations for a job well done. Thank you for allowing me to be a big part of this family.

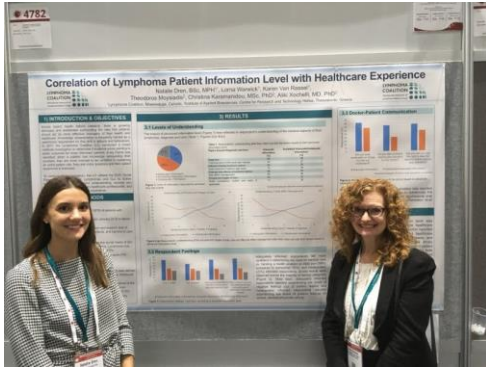
As we turn our attention to business at hand, no one is better suited to take you to the next level than Lorna Warwick. As the [announcement highlights](#), Lorna brings more than 25 years of experience in the charitable sector, including 20 years working in health related charities and many of those years has been in haematology. Her dedication to this field, her compassionate heart and her desire to be a strong advocate will bring exceptional results. You are in very good hands.

The *2018 Report Card on Lymphomas: Spotlight on the Patient Experience* is now [available online](#). Using the data gleaned from the 2018 Global Patient Survey, an analysis was conducted to discover common issues and unique insights as patients move along the care continuum.

Overall, the report shows that all patients require more information and support to help them cope with their lymphoma, and there are times within the patient experience when specific topics should be clearly addressed or actions taken. Patient organisations have an important role to play, alongside healthcare professionals, in ensuring patients receive the right information and support needed, at the right time, to build their confidence, improve their overall experience, and improve outcomes. I encourage you to read the report, now [available here](#).

Also new to the LC website is the paper [Fear of Cancer Recurrence](#). This paper summarises ongoing clinical studies in this area and includes clinical guidance, based on the studies. Cancer brings with it an emotional impact, in addition to the physical impact, right from diagnosis. Fear of relapse is a common occurrence across cancer types and ensuring patients are made aware this fear often happens can reduce the stigma of the fear, reduce anxiety and encourage the patient to discuss how they are feeling. If patients discuss their feelings, any fear can be addressed early and patients can be directed to the right support as required.

Finally, a reminder that the LC abstract, ***Correlation of Lymphoma Patient Information Level with Healthcare Experience***, was presented on 3 December at the [American Society of Hematology Annual Meeting & Exposition \(ASH\)](#). Read the abstract [here](#). An ASH summary will be prepared and distributed in the near future.



Thank you to all of the LC members and lymphoma community who helped share the 2018 Global Patient Survey and a special thank you to the patients who participated, providing the research to make this work possible.

I wish you a peaceful holiday season and a well deserved rest.

Warmly,

A handwritten signature in cursive that reads "Karen".

Karen

RESEARCH NEWS

- How I treat breast implant-associated anaplastic large cell lymphoma [READ MORE](#)
- Atrial Fibrillation: Considerations for the Use of BTK Inhibitors [READ MORE](#)
- Patient-reported distress in Hodgkin lymphoma across the survivorship continuum [READ MORE](#)
- Prevalent Epigenetic Modifier Mutations Found in Follicular Lymphoma [READ MORE](#)

LRF PATIENT FORUM



Natalie Dren and Karen Royds, pictured above, attended Lymphoma Research Foundation's *North American Educational Forum on Lymphoma*. The 3 day event provides critical information on treatment options, patient support issues, clinical trials and the latest advances in lymphoma research to people with lymphoma and their loved ones.

INTERNATIONAL SYMPOSIUM ON HODGKIN LYMPHOMA

More than 1,100 delegates from over 70 countries participated in the International Symposium on Hodgkin Lymphoma in Cologne, Germany October 27-29. While survival rates overall for Hodgkin lymphoma are high, there is still a need for new therapies for hard-to-treat patients like those over age 50 when diagnosed and those who relapse or are refractory to treatment. In addition, all patients need access to therapies that are less toxic to reduce short and long-term side effects. Lorna attended the conference and was able to present data from the LC global patient survey showing the Hodgkin lymphoma patient experience. The abstract book from the conference is available [here](#).

Thank you to all of LC's sponsors who have contributed to our efforts this year. Without them giving back to the lymphoma community, we would not be able to work towards our mission and vision.



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This has been a wonderful few weeks of connecting with Lymphoma Coalition members across four different meetings in the region.

Lymphoma Coalition (LC) was represented at the 2018 International Conference on Cancer Nursing (ICCN 2018), the annual meeting of the International Society of Nurses in Cancer Care (ISNCC), held in September in Auckland, New Zealand. The focus was on all cancers and saw attendees from all over the world, especially from the Asia Pacific region.

The UICC's World Cancer Congress (WCC) was held in Kuala Lumpur in September. This

was a valuable meeting to attend and allowed LCAP members from India, China and Korea to connect. Each member organisation presented during the conference, demonstrating the calibre of their work.

A further regional meeting was at the [Australasian Blood Conference](#) in Brisbane, Australia, with another three LC members in attendance.

All these meetings provided opportunity for discussion regarding plans for the region, which will include providing programmes to build skills in advocacy, capacity building and education platforms.

November 23-25 saw the [ESMO Asia](#) meeting (in Singapore) held for the third time. This included an inaugural round table meeting on rare cancers, and the launch of Rare Cancers Asia, a multi-stakeholder partnership hosted by ESMO. The aim of the meeting was to bridge the gap between Asia and Europe, so everyone can work together on the challenges faced by patients, physicians, researchers, industry and other stakeholders in Asia Pacific.

LCAP IS PROUD OF ITS MEMBERS

House 086 presented at WCC on their use of the LC Global Patient Survey results and how the data has impacted their practice and work with patients. In 2016 House 086 began collecting patient data independently to try to drive change in China, resulting in a living report of Chinese lymphoma patients. The first report provided fresh evidence of the heavy financial burden on patients.

In 2018 they used the LC GPS and focused their efforts on the fact that the more information that is provided, the more benefits the patient will gain. As a result House086 have redirected their services and deepened their online and offline services for newly diagnosed patients, including a new in-person patient education program and a new [Living with Lymphoma booklet](#). They are in the midst of planning a related new patient healthcare project to be piloted in 3 hospitals, with the intent to roll out to at least 20 hospitals throughout China.

LYMPHOMA COMMUNITY ADVISORY BOARD (CAB)

The CAB is now recruiting members, and is looking for people to act as passionate advocates for the whole lymphoma community in Europe. The CAB aims to:

- Influence the research and development pipeline for lymphoma (including CLL) treatments to better meet the needs of patients.
- Increase access to, and reimbursement of, lymphoma

ESMO 2018 REPORT

A report on ESMO is now available [here](#). If you have any questions, please direct them to [Natacha](#).

NEWS FROM EUROPE

3rd General Assembly for Partners

(including CLL) treatments across Europe.

- Improve awareness and understanding of lymphoma (including CLL).
- Create a louder voice for the lymphoma and CLL patient community.
- Recruit, train, and support more patient advocates and experts for individual countries and Europe as a whole.

If you have any questions, please contact [Jonathan](#) or [Natacha](#).

LCE IS PROUD OF ITS MEMBERS

Infographic about CLL and Mantle cell lymphoma launched in Serbia

There is a lack of information about chronic lymphocytic leukaemia and mantle cell lymphoma available in Serbia, so patients often remain uninformed or insufficiently informed about their illness. The Serbian Lymphoma Group (SLG) and the Lymphoma Patients Association (LIPA) jointly designed infographics for patients with CLL and MCL in order to help them better understand the onset of the disease, therapeutic options and what to expect during and after therapy.

Given that there isn't a national lymphoma patient registry in Serbia, meaning there isn't any precise data on the number of patients diagnosed or treated, data from the Clinical Centre of Serbia was extrapolated to the national population.



Kraujas involved in Health policy

OHLB "Kraujas" seeks constructive and effective dialogue between patients, doctors and health regulators, and actively participates in health policy in Lithuania, expressing the community's position on relevant topics, representing the interests

and Associated Members

The HARMONY Alliance is a pan-European project with a strong potential for global impact, as there is no similar big data project in haematology bringing academic study groups and industry data together into one analytics platform. It has taken HARMONY two years to tackle legal, data anonymisation and IT issues, but now the first data from thousands of patients is being uploaded into the platform. Consequently, decisions are now being made about the initial research projects that will be able to utilise this data, including the clinical questions and how these projects will incorporate patient needs e.g. patient reported outcomes (PRO).

Some of the key topics where **LCE** will provide input include:

- Ethical questions about anonymisation, informed consent and similar issues
- Delphi survey on Core Outcome Sets in all Hematologic Malignancies
- Collecting, processing and systematically providing real-world data to key opinion leaders (KOLs) and other stakeholders
- Understanding how patient groups can submit research proposals once the platform is up and running
- Making sure that patient involvement is consistent and systematic at every stage

A meeting was held in conjunction with ASH and it has been decided that the initial lymphoma project will focus on T cell lymphomas.

of blood cancer patients and expressing their need and the problems that patients face. Their work includes:

- Proposals for amendments to legislation
- Requests for reimbursement of treatments
- Participation in working groups of the Ministry of Health of Lithuania.

